

FOLLOW-UP STUDY DIRECT PAYMENTS IN SWEDEN

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I. GENERAL

This article needs to be considered as a continuation of the first study of the Expertise Centre Independent Living: "Direct payments in care. Actual situation in 8 European countries". The study showed that Sweden and the Netherlands are particularly interesting countries which may still offer many new insights for Flanders. We have thus started a follow-up study which explores some aspects further into detail.

This article starts with an overview of the general Swedish context. Further on, important aspects of the Swedish practice of Personal Assistance are being highlighted. The article concludes with the questions that will be investigated more thoroughly in cooperation with a Swedish organization.

HISTORICAL CONTEXT

The first initiatives for disabled persons can be situated in the 19th century when the first institutions were built.

From the 1960's onwards a first policy-shift started. For the first time there was a serious reflection about a policy for disabled persons which focused on the adaptation of the environment and on social intercourse with disabled people in order to integrate the latter.

Within this framework there were initiatives focusing on housing and living. Between 1965 and 1975 1 million flats were made accessible in the so-called 'million programme'¹. The problem however was that the buildings as such were made accessible but not the actual living units. In 1978 a new law entered into effect which made it obligatory for residential buildings to make the main entrances as well as the entrance of the individual living units accessible for disabled people. As a result nowadays more than 10 % of all buildings in Stockholm are accessible to disabled people.²

The support of intellectually disabled people in those days consisted of services and utilities. Those with a physical deficiency could only go to specialized schools. The problem was that there was no reception nor support for people older than 18 years which meant those people were either sent back home or sent to a nursing home for the elderly. It was clear something had to be done. A first alternative was "FOKUS living". A parliamentary investigation in the 80's however revealed that such a way of support could not guarantee an independent life. As a reason for the failure of this project disabled people mentioned the factors collectivism and a lack of professionalism.

In 1987 STIL (Stockholm Independent Living) started an experiment with personal assistance in which the means that would otherwise go to other services were spent

¹ Berg S., Personal Assistance in Sweden. Independent Living Institute, 20-05-2003

² Ratzka A., Independent Living for people with disabilities: from patient to citizen and customer. Keynote at the conference in Barcelona, Independent Living Institute, 22-10-2007.

on personal assistance. For two years this system was tested in different municipalities until 1994, when the actual legislation saw the daylight.³

ACTUAL FORMS OF ASSISTANCE

PERSONAL ASSISTANCE

Personal assistance is regulated through two bills:

- On the one hand there exists the so-called LSS = “Lag om Stöd och service till vissa funktionshindrade” (Bill on the Assistance and service with certain functioning problems). LSS takes care of ten or so services for disabled people on the municipal level. One of these services is Personal Assistance for people who need less than 20 hours of assistance per week for basic assistance needs. One may receive the assistance in the form of direct payments or through a municipal service. The municipality can decide in your place which form of assistance you will be receiving. Whether the municipality actually does decide in your place depends on the municipality itself.
- On the other hand you have LASS or “Lag om assistansersättning” (Bill on the compensation for assistance). LASS does only regulate the assistance for persons with a serious deficiency, with an assistance need exceeding 20 hours per week. This assistance only comes in the form of direct payments and falls under the so-called ‘försäkringskassa’, i.e. the social security system⁴.

One can organize the employership in different ways. Either you are your own employer or you hand over the employership to a municipality, a private for-profit organization or a private non-profit cooperative society.

For the moment there are 19 000 persons receiving Personal Assistance. Amongst them you have 15 000 LASS users and 4 000 LSS users⁵.

RESIDENTIAL OFFER

Officially there no longer exist real utilities and services in Sweden. However, there are some so-called residential agreements with specialized services and ‘community based services’. In most cases, this comes down to Group accommodation and guided living with maximum 5 persons, each having their own room. But the residential agreement may also consist of 5 to 10 individual apartments in one and the same building-block. For children long term residential facilities no longer exist.

There are two bills which regulate all this, one of which is LSS, the other one being SOL⁶. SOL is a bill not only intended for disabled people but also for e.g. elderly people. LSS is only destined for disabled people. These services can be offered by private for-profit organizations.

³ Berg S., Personal Assistance in Sweden. Independent Living Institute, 20-05-2003.

⁴ Van Hauwermeiren J., Decruynaere E., Directe financiering in de zorg: stand van zaken in 8 Europese landen. Expertisecentrum Onafhankelijk Leven. 02-2009, pp13-16.

⁵ Ratzka Adolf, e-mail aan Van Hauwermeiren J., 31-03-2009.

⁶ Hayward R., Country Report Sweden. In: Beadle-Brown J., Kozma A., Deinstitutionalization and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 2007, pp524-541.

Services that fall under LSS legislation can be offered by any organization. Under the terms of SOL it is only the local government which may decide who can and who cannot offer this service.

The services offered by private organizations are not specially monitored by the government and no qualifications are required for the staff working for these services.

These services cannot be paid with direct payments, but receive money directly from the government (shared financial responsibility of the national and municipal level). With SOL the person sometimes has to pay a personal contribution⁷.

MACROBUDGET

The entire budget spent on the assistance of disabled people is not easy for Sweden because of the fact that the budget is spread out over different levels. The general planning as well as social security are situated on the national level. Municipalities are responsible for social services and the provinces take care of health care. Sweden has approximately 9 million inhabitants of which 130 000 have a physical deficiency (45 000 people having a serious deficiency) and 150 000 have a psychiatric ailment. For mentally disabled people no data are available.

The number of persons that receives any form of assistance from LSS is 56 000 to 58 000, which makes up for 0.6% of the population. In 1994 the total amount for health care accounted for 8.4% of the GDP⁸.

Also personal assistance is a competence shared by the municipal and national level. LSS is being financed on a municipal level, LASS has been entirely financed by 'Försäkringskasse' up until 1997. As from 1997 the 'Försäkringskass' only pays for the hours exceeding 20 hours of assistance per week, the rest is financed by the municipality.

The number of persons receiving personal assistance was 19 000 in 2008 (15 000 of which suffering a serious deficiency). That is 0.2% of the population. Between 1994 and 2004 the costs for this type of assistance rose by 15% on average annually⁹.

If we only look at LASS we may estimate the total amount which will be spent on this type of assistance in 2009. If we take the average number of hours per week (100) and on that basis make a projection for the whole year for all LASS-users combined, then we get the number of 1.95 billion euro. Approximately half of that amount flows back to the state in the form of general taxes and income taxes.

⁷ Berghäll P. (Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

⁸ Hayward R., Country Report Sweden. In: Beadle-Brown J., Kozma A., Deinstitutionalization and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 2007, pp524-541.

⁹ Ratzka Adolf, e-mail aan Van Hauwermeiren J., 31-03-2009.

II. PERSONAL ASSISTANCE

ASSESSMENT

In principle it goes as follows: the municipality has to investigate your need for assistance or support and express it in a number of hours of assistance per week. This happens upon a domestic call. If the municipality esteems that you need more than 20 hours of assistance per week, you will be referred to the 'Försäkringskasse'. You may also apply for this yourself. If you need less than 20 hours of assistance per week you will fall under LSS legislation, i.e. a municipal responsibility.

If the municipality or yourself make a demand at 'försäkringskassan' then it will first be checked whether more than 20 hours of assistance per week are really necessary for your basic needs, and this according to the aforementioned 'eye of the needle' principle. Once you have passed this first test, you will be assigned a certain number of hours of assistance in accordance with your real assistance needs¹⁰.

In what follows we will mainly discuss people who fall under LASS legislation and who as a consequence receive direct payments.

In the assessment all domains of life pass in review. According to the law the assistance provided should enable you to take up your responsibilities as is common in a regular Swedish family¹¹. There are activities for which you may not receive assistance, such as assistance during school hours, daily activities for intellectually challenged persons, hospital time, etc. The reason for this is that is supposed adequately trained personnel is present in these locations¹².

Concerning assistance at school: this was allowed up until 1996 and afterwards this was changed. Exceptions are allowed and these exceptions actually still occur quite frequently¹³. During the assessment not only your need for assistance is scrutinized but also your planned activities. This makes up for the fact that two persons with the same assistance needs do not receive the same budget: some people have more activities planned¹⁴.

You may also ask for assistance for matters that could formerly only be taken care of by persons with a specific training. For example: taking care of bodily injuries, replacing tubes, administering medication, help with breathing devices, physiotherapy, etc. It is the disabled person's doctor who determines whether something falls under 'selfcare' and whether it can be carried out by assistants or not¹⁵. This is an interesting fact given the discussion about the decree about care and care assistance in Flanders.

¹⁰ Ratzka A., e-mail aan Van Hauwermeiren J., 31-03-2009.

¹¹ Ratzka A., The Swedish Personal assistance act of 1994. Independent Living Institute, internet, 23-06-2004.

¹² Berg S., Personal Assistance in Sweden. Independent Living Institute, internet, 20-05-2003.

¹³ Blanck C., Scherman A., Sell K., Ten years with personal assistance. A report from the Knowledge Project., JAG, Stockholm, 2006, p28.

¹⁴ Berghäll P.(Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

¹⁵ Blanck C., Scherman A., Sell K., Ten years with personal assistance. A report from the Knowledge Project., JAG, Stockholm, 2006, p32.

It was revealed that the number of assigned hours of assistance depends amongst other things on whom you have chosen as employer. Private (non) profit organizations will often sue the national social security to obtain more hours of assistance for their clients. If you are your own employer this is much harder and municipalities acting as an employer seldom or never go to court¹⁶.

BUDGET CALCULATION

Once your number of hours of assistance is calculated, the number is multiplied with a fixed amount (for 2009 this is around 25 euro, and it is recalculated annually in accordance with inflation) and you will receive the resulting amount in the form of a budget. This fixed amount may be raised by 12%¹⁷ in exceptional cases, for instance when specific skills are required of the assistant.

The budget amount is recalculated every two year¹⁸. With the budget received you'll have to try and cover for the wages, social security, administration, training, possible travel expenses etc. of your assistants¹⁹.

EMPLOYERSHIP

The municipality carries a fairly great responsibility for personal assistance. They are the first and main contact point and should ensure the rights of disabled persons are respected. Criticism arises about the fact that municipalities do not take up this responsibility in many cases, which results in disabled persons having to defend their rights themselves.

The employership can be organized in different ways. Either you are your own employer, or you hand over the employership to a municipality, a private for-profit organization or a non profit private cooperative society.

Even when the employer is not the municipality the latter still has a certain obligation. They have to provide replacement of your assistant in case of illness, regardless of who the employer is²⁰.

In 2008 3% of the users were their own employer, in 51% of the cases the municipality was the employer, 11% worked with a cooperative society and 35% worked with a private organization²¹.

¹⁶ Berghäll P.(Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

¹⁷ Boeykens J., Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Niet gepubliceerde scriptie, vakgroep pedagogische wetenschappen, 2007, p.17.

¹⁸ Ratzka A., e-mail aan Van Hauwermeiren J., 31-03-2009.

¹⁹ Boeykens J., Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Niet gepubliceerde scriptie, vakgroep pedagogische wetenschappen, 2007, p.17.

²⁰ Boeykens J., Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Niet gepubliceerde scriptie, vakgroep pedagogische wetenschappen, 2007, pp11-21.

²¹ Ratzka A., e-mail aan Van Hauwermeiren J., 31-03-2009.

MUNICIPALITY

Although important differences between the different municipalities exist, we may state that the municipality is generally speaking somewhat less customer-oriented and assigns a lower number of hours of assistance than private organizations do.

The municipality determines the assistant's wages and also plays a role in the recruitment of assistants²².

The freedom you have in order to organize your assistance (who, when, when) varies between each municipality. In principle the municipality should provide training for the assistants, but this isn't always the case.

A woman who had participated in a survey indicated that she had worked for a longer period with the municipality acting as employer. In this way she tried to determine who were to be her assistants, when she would receive assistance and also where. After a long and fierce battle with the municipality she finally indicated that the collaboration with the municipality was untenable and she decided to join a cooperative society. From that moment on she realized that what she had fought for all this time was a reachable goal and she is now very satisfied about the assistance she gets.

COOPERATIVE SOCIETY

People working with a cooperative society can determine the wage of their assistants themselves. Moreover this private non profit organization does not have to comply with specific government-imposed quality standards²³.

Although there exist some differences between the different cooperative society's working methods, we would like to illustrate their working methods in general using two examples.

The STIL cooperative society could serve as a first example.

One of the basic tenets of personal assistance is that one can determine for him or herself who provides assistance, what assistance you get and where you get it. How is it possible to guarantee this right if you assign this task (i.e. employership) to another person or organization? STIL makes a difference between the 'leader' ('werkleider' in Dutch) and the employer. The 'leader' is the disabled person and he or she decides about the who/what and when of the assistance. STIL takes care of the administration, the taxes due to the authorities, pays out the wages, helps people with labour-disputes and defends the rights of its members in conflicts with the 'försäkringskassa'²⁴.

²² Berghäll P.(Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

²³ Berghäll P.(Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

²⁴ Ratzka A., The Swedish Personal assistance act of 1994. Independent Living Institute, internet, 23-06-2004.

STIL however, does not help with recruitment of assistants because they believe in the principle of 'growth through personal responsibility'²⁵. They do organize trainings and peer advice sessions about managerial tasks but the recruitment is left to the disabled person himself.

STIL also makes sure that members are closely involved in the organization. For example: only users of assistance may become member of the cooperative society and be a member of the board. Also the director and a part of the staff are disabled people or users of personal assistance²⁶.

We will take a look at a second example as well: the JAG cooperative society, an organization that works with people with multiple deficiencies of which one is an intellectual deficiency. It is interesting to note that in Sweden, as in Belgium, exists a system of personal or legal representative for disabled people. This representative is appointed by court and is responsible for the number of hours of assistance that are assigned to the disabled person. The representative also decides who becomes the disabled person's employer. In practice it is often the case that this representative becomes the 'service guarantor' in JAG although he or she may also leave this task to somebody else.

What is a 'service guarantor'? Usually it is a family member who does this job voluntarily and who is responsible for the recruitment of suitable assistants and organizing assistance in accordance with the needs and expectations of the disabled person. The cooperative society JAG takes care of administrative tasks. In a report issued by JAG concerning its ten-year long experience with personal assistance we can read that the 'service guarantors' generally take their task serious and really try to involve the disabled person in the organization of their assistance.

The JAG members are also involved in the organization in another way. Some disabled people reside on the board of the 'JAG organization' (cooperates with the JAG cooperative society) and some of them have a voting right in the annual general assembly. There also exists a JAG centre where members may participate in lobby work and opinion-leading. Within the framework of the activities of this centre the members also attend seminars, trainings and so on.

Considering the fact that the board of the JAG cooperative society carries a great responsibility it is often the 'service guarantor' instead of the disabled person who participates in the activities of this board²⁷.

PRIVATE FOR PROFIT ORGANISATIONS

In Sweden you may make use of private for profit organizations who act as the employer. These organizations do not have to render account to the authorities, they do not have to comply with specific quality standards and are treated as any other private company. It is supposed that the budget holders can independently judge whether these organizations

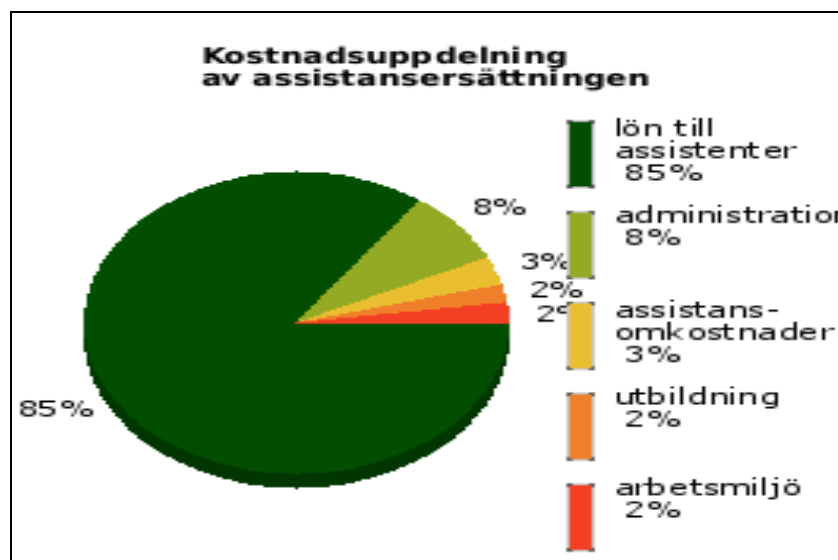
²⁵ Egan D., Issues concerning Direct Payments in the Republic of Ireland. A Report for The Person Centre, 11- 2008, p6.

²⁶ Ratzka A., The Swedish Personal assistance act of 1994. Independent Living Institute, internet, 23-06-2004.

²⁷ Blanck C., Scherman A., Sell K., Ten years with personal assistance. A report from the Knowledge Project., JAG, Stockholm, 2006, p32.

offer good quality assistance. Depending on the business model of these organizations you may choose the wage of your assistants yourself²⁸.

Below you can see an example of the budget repartition of such a private organization²⁹.



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|---|-----|
| Wages or labour costs for assistants | 85% |
| Administrative costs and benefit | 8% |
| Training costs for assistants and 'leaders' | 2% |
| Paid out costs for assistants | 3% |
| Work surroundings and personnel costs | 2% |

EXPENDITURE FREEDOM

One may freely decide how to spend the budget. Every month you will have to indicate in a timesheet the number of hours of assistance used. Every six months you have to account for your expenses to 'försäkringskassan'. The number of hours of assistance unused have to be refunded. In between the six months it is easy to shift hours from week to week or month to month: otherwise said, this means you do not have to use the same number of hours of assistance every month or week³⁰. If you have motivated a request for specific assistance and if you have obtained a raise of your budget (i.e. the fixed amount multiplied by 12%), then you will have to give a more detailed report of your expenditure.

²⁸ Berghäll P.(Assistansbolaget i Sverige AB, Örebro, Sweden) e-mail aan Van Hauwermeiren J, 17-06-09.

²⁹ <http://www.independentliving.org/assistanskoll/profil-orebro-AssistansbolagetiNorden.html>

³⁰ Ratzka A., The Swedish Personal assistance act of 1994. Independent Living Institute, internet, 23-06-2004.

You may spend the budget on informal care on the condition that you hand over the employership to the municipality, a cooperative society or a private organization³¹. If you move abroad, you may take your budget along³².

LEGAL SECURITY

Since the entering into effect of the new LSS legislation in 1994 personal assistance has become a right in Sweden. This means that everybody who demands personal assistance and is entitled to it according to Swedish law has to receive assistance, regardless of the budget which is at disposal. People entitled to assistance are: Persons with a developmental disorder, autism or autism spectre disorders (target group 1), persons with a considerable intellectual deficiency after brain damage at a higher age, caused by external violence or bodily disease (target group 2), and persons with a permanent physical or psychic deficiency (target group 3). As a result waiting lists do not exist. It may happen though that people have to wait a while before they get the green light for receiving assistance. Persons from target group 1 and 2 will get approval on the basis of a diagnosis. Persons from target group 3 will have their assistance needs assessed upon a domestic call. This should take only 180 days at maximum³³.

³¹ Boeykens J., Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Niet gepubliceerde scriptie, vakgroep pedagogische wetenschappen, 2007, pp11-21.

³² Ratzka A., The Swedish Personal assistance act of 1994. Independent Living Institute, internet, 23-06-2004.

³³ Boeykens J., Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Niet gepubliceerde scriptie, vakgroep pedagogische wetenschappen, 2007, pp11-21.

III. A FEW CONCLUSIONS

Some important issues are revealed by this study.

- Sweden has paid attention not only to personal assistance but also to housing and living. It may be interesting to take a closer look at their legislation concerning housing and living and try to find out to which extent these accessible housings have contributed to an independent life.
- Budget setting is carried out on the basis of 'needs' and 'lifestyle'. The amount of care needed as well as planned activities are taken into consideration. This is not the case in Flanders where only the amount of care needed is taken into account.
- The number of hours of assistance in Sweden is often depending on who is the employer of your assistants. People who join a private organization often receive more hours of assistance. We are more particularly interested in where the line is drawn concerning the number of hours of assistance considered 'socially responsible'.
- In Sweden it is possible to hand over the employership and to differentiate between 'leader' and 'employer'. In this way you discharge the person with a budget of a great administrative burden. In Flanders the regulations are more difficult. Only temporary work agencies can act as employer. This makes up for the fact that Flemish budget holders associations can not offer assistance in the same way as the Swedish cooperative societies do. Research on the Swedish legislation in question is recommended.
- Within the framework of the decree on care and care assistance it is interesting to note that assistants in Sweden may carry out specific 'medical' tasks. It is the disabled person's doctor who determines which tasks the assistant may or may not carry out.
- Accounting for your budget is a totally different process in Sweden. You only need to indicate in a timesheet the number of hours of assistance used. You receive 25 euro per hour and you may independently decide how much you pay your assistants. There is no price-setting of the assistant's wage.
- Within the JAG cooperative society the work of the 'service guarantors' is voluntary work. They often act as 'leaders' and assistants both at the same time. It could be interesting to find out how this double role is perceived and experienced by the 'service guarantors'.
- More and more people in Sweden choose a private for profit organization to act as their employer. In Flanders the discussion about the role of the market in the care is a hot topic. A study into the functioning of these private profit-generating organizations could result in interesting information.
- The question whether the municipalities do provide easily accessible information is a point of interest.

These remarks will be forming the foundations of a future research proposition. The research will be carried out by a Swedish expert of direct financing. Several candidates will have the chance to sign in upon the research proposition. The Expertise Centre will choose the most appropriate person out of all candidates.

Let this be a soliciting call to Swedish experts: if you are interested in cooperating with us for this specific research, please contact us. The results of the study are expected around May 2010. They will be published in our newsletter.